‘The Doctor Will See You Now’ - Examining the Experience of Claiming Disability Benefits in an Age of Austerity

Kainde Manji, University of Glasgow

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Overview

- Background and context of reforms
- Independent living
- Conceptions of agency in policy development
- Experiences of disability benefit claiming
  - Applying for benefits
  - Assessment & Reassessment
  - Expected behaviours
- Discussion and Conclusions
## Reforming Disability Benefits

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Employment Support Allowance

- Replaced IB from 2011
- Work capability assessment – administered by ATOS since 2011 (New contract to be tendered)
- Three categories:
  - Support Group
  - Work related activity group – 12 month time limit
  - Fit for work > move to JSA
Personal Independence Payment

- Care component (Higher and Lower) & Mobility component (Higher and Lower) – No middle rate care.
- New eligibility criteria established by independent assessment
- Abolish indefinite award and introduce 3 yearly re-assessment.
- Funded at DLA 2010 levels = 20% real terms cut in funding
- Similarities with ESA?
Independent Living?

“Independent living means all disabled people having the same freedom, choice, dignity and control as other citizens at home, at work and in the community. It does not necessarily mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life.” (Independent Living in Scotland Project – original emphasis)

- DWP state PIP will enable disabled people to achieve greater independence and exercise more control over their lives (DWP 2011)

- Language of disabled people’s movement co-opted by neo-liberal agenda (Morris 2011)
Understanding Agency

- Wright (2012) defines agency as ‘relational, dynamic, differentiated, interconnected, interdependent, intersubjective and interactive’

- Critique of policy design based on narrow conception of agency - self interest (Wright 2012).

- Focus is on behaviour of claimants rather than motivations of policy makers.

- Benefits increasingly stigmatised and stigmatising (Garthwaite 2011).

- Lived experience ignored – impact on agency and sense of self.
Methods

- Three year ESRC/Scottish Government PhD Research Project impact of welfare reform on disabled people in Scotland

- One-to-one semi-structured interviews with 23 individual disabled people claiming at least one of DLA, IB/ESA or other disability benefit.

- Conducted between November 2013 and July 2014.

- Recruitment:
  - Disabled People’s Organisations
  - Disability Charities
  - Social Media

- NB Interviews took place Pre Smith Commission – recommendations include to devolution of DLA.
Applying for benefits

Filling in the form:

My wife has a degree, or two. I’ve got various higher education qualifications. It took us two days to do the forms. Even though we’d done similar forms before. “(Adrian, 50)

So [I] applied for DLA. I spent quite a bit of time filling out the form [...] the DLA isn’t geared very well to, um, I guess more so it suggests being geared towards rejecting people, but the idea of variable conditions and hidden conditions and things that, you have to pick your worst day, or do you try to average it? (Thomas, 33)
Applying for benefits

Importance of knowledge:

“I didn’t just approach it haphazardly. I didn’t, you know, just fill in any answers to the form. I was very very careful how I approached the form and put in all the details about my condition, and I really didn’t miss anything out.” (Harry, 60)

“I was rejected, obviously because it’s really difficult. I could show them how difficult my life was, I could show them what medication I was on, but I couldn’t tell them what’s wrong with me. So they couldn’t, they just wouldn’t give me it for that.” (Fiona, 28)
The Assessment Process

The experience of being assessed:

ESA:

“It was terrifying, and it was a horrible experience. You know, it was very demeaning that you had to basically you had to put yourself to as nearly dead, you know? To apply for this, and I didn't want to be doing that.” (Lewis, 46)

DLA:

“And it was really, I’ve never felt so... it’s really disempowering actually. It’s a really really disempowering experience because you are an object, you suddenly become an object and it’s almost like your agency is completely stripped from you and particularly there’s no kind of... there’s no focus on a person’s feelings at all.” (Catriona, 29)
Mistrust of the system

“It’s when you go to jobcentre or medical assessments that’s when you’ve got to be really scared. Coz you don’t know what to say to them. And they ask you all the questions all over again like you’ve not heard before. They keep going round in circles.” (George, 50)

“You know, I could be talking to a dentist, who has no expertise on my disability. [...] I asked what their expertise was in my disability. Again, if you ask the relevant questions, you don’t get answers. They wont give you an answer, because they don’t know.” (Lewis, 46)
The Assessment Process

Assessment for DLA:

“It was one of those things, you know, it could be quite intrusive having someone come into your house just to assess you, but also there were parts of it that were really accessible because they could see me in bed, and this is how I spend most of my day.” (Thomas, 33)

“If they could come and see me at my absolute worst. When I’m at my absolute worst, my absolute worst case scenario is when my legs play up [...] you’re hardly going to invite, like ask the doctor to come round and sit and have, like if they sat and interviewed you then, then they’d be like oh my god.” (Fiona, 29)
“You’ve no idea the period. Again you hear stories of some people it’s every three years and others it’s every three months. So you sit there every day, waiting for the post to come. Is that brown envelope coming in? And that doesn’t help. And if they actually were consistent, and they said – you’ve now got a three-year period, or even a year’s period. But the thing is you don’t know. It’s Chinese water torture, you just don’t know when the next one’s coming.” (Adrian, 50)
Assessments for PIP

Proposed new assessment regime:

“I don’t want to be assessed by some quack, or by some guy who works for Atos, or something like that. I mean I just don’t want that, but at the same time, I guess I’m in conflict with myself because I guess I know that if everybody just said, oh well never mind, I just won’t have it... and actually I’m sure that the government, that’s how the government will save quite a bit of money, is that there will be lots of people who say, you know what, that’s just not worth it to me.”(Catriona, 29)
Assessment for PIP

Proposed 20 meter rule

“It absolutely terrifies me [...] Twenty metres... it’s nothing... you know! And one day I might be able to do it. I don’t think I could walk my 20 metres, but one day I could struggle and maybe get there very slowly, but most days I couldn’t walk that. You know, but if they, they have their own test indoors, which doesn’t balance out with what it’s like on different surfaces.” (Sheila, 62)

“I just think that’s absolutely ridiculous. I mean, you know, walking is not a judgement of your condition and as I say, the condition can vary.” (Harry, 50)
Expected behaviours

“I went on crutches and I’m not saying that I don’t use my crutches, but I felt as if like, you feel as if you’re putting it on. But I was thinking like, you just have to think of this as your worst day ever so that they can see what that’s like [...] I was told [by a welfare rights advisor] not to be too smart in what you were wearing, and don’t make an effort with your hair, and just put it up in a pony tail or something, like wear odd socks, literally look like you’re not well. That’s what they were advising me to do because the doctor is obviously looking at things like that. [...] And they’d say things like they’re watching you when you’re doing anything so don’t’ get up off the couch too quickly, watch, and they made me like take off my socks and shoes to see how I moved about and they wanted me to not move about too fast and see when you’re doing things, and that’s what I mean, you feel like you’re acting, and you shouldn’t be doing that.” (Fiona, 28)
Expected behaviours

“I guess in her interview she was a bit naïve. She didn’t... she’s more inclined to say ‘oh well, I can do it sometimes’ which is always the wrong thing to say, you know, in those circumstances. You have to look at the worst-case scenario rather than the best case.” (Jayne, 61)

“I was aware then when I was filling them in of kind of how much you have to talk about what you can’t do. [...] if someone were to ask me, in my everyday life, kind of how far can you walk without it being sore, I think I would probably exaggerate how far I could walk. [...] And then I was confronted with a form where actually if you were to do that, that’s the difference between getting something and not getting something.” (Catriona, 29)
Surveillance

“He [Atos assessor] can even tell you what I’m smoking. [...] it’s scary. Why do they put that down on the medical report? Whether I smoke is nothing to do with them. They’re saying, ah he’s smoking, we’re giving him too much money.” (Liam, 46)

“I don’t go out and join things, because if – and again, it’s completely mad – but if I did go out and join things, what little money the government gave me would be taken away because I would be deemed fit for work. Which I know is mad, but it’s actually counter productive, because instead of helping me into a work situation, if I was capable of doing [that] [...], instead of providing support to get me to work they say – you’re either ill, and therefore you have to stay at home and be miserable and feel guilty about it. Or, you’re well enough to do a full time job without any support.” (Adrian, 50)
Surveillance

Atmosphere of mistrust:

“I think it could be used against me and I think it’s quite sad that people aren’t able to talk about or even, other people are even quite reluctant to do stuff, in case they think it goes against them.” (Anthony, 46)
Discussion & Conclusions

- Application process becoming more complicated, harder to claim, and less transparent.
- Assessment criteria giving greater emphasis to medical criteria than barriers to participation.
  - Anxiety & unmet need?
- System is based on narrow assumptions about behaviour and agency CR Goffman (1968) and Wright (2012)
  - Leading to an atmosphere of hidden conditionality?
Discussion & Conclusions

“Independent living means all disabled people having the same **freedom, choice, dignity** and **control** as other citizens at home, at work and in the community.”

- Policy increasingly out of step with disabled people’s realities and requirements of independent living.
  - Impact on sense of self?
    - The way disabled people view themselves and their role in society. (Dignity & Freedom)
  - Impact on agency?
    - Ability to make choices about their own needs (Choice & Control)
References

• Beatty, C. and Fothergill, S. (2011) Incapacity Benefit Reform: the local, regional and national impact. Sheffield: Centre for Regional Economic and Social Research


